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Cleft Nursing CEN

- Identified tongue tie practitioners are ideally placed to examine an infants palate as part of their own routine assessment
- Working together with APT to provide additional learning opportunities to incorporate palate examinations as part of routine practice



Cleft Nursing Clinical Excellence Network
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What is a cleft?

- Unknown cause
- Combination of genetic and environmental factors

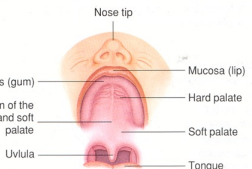
Incidence

- 1 in 700 births worldwide
- 1200 within the UK
- Up to 50% cleft palate only
- More common in girls
- Isolated or syndromic
 - 30% of CP cases are syndromic – Pierre Robin Sequence, 22q11 deletion, Sticklers



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Function of the palate



The diagram illustrates the internal structures of the human mouth and throat. Labels on the left side include: Nose tip, Alveolus (gum), Junction of the hard and soft palate, and Uvula. Labels on the right side include: Mucosa (lip), Hard palate, Soft palate, and Tongue. The diagram shows the hard palate (the bony front part) and the soft palate (the fleshy back part) meeting at the junction. The uvula is at the very back. The tongue is shown at the bottom, and the alveolus (gum) is at the top.

- Feeding
- Speech Development

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Normal swallowing action involving the lip seal, tongue movements and effective palate closure

Mechanisms of feeding

The normal feeding mechanism requires an effective oral and pharyngeal thrust with tongue movements moving, alternating regions and pressure forces to be built into the mouth and passed to force the swallowed.

First, negative pressure (-) phase:

First stroke is initiated by lip and palate, tongue depressed below palate and along food in from the nipple to food (blue arrow)

Negative pressure created by lips forming a seal around the nipple and the tongue moving down to seal. Food is taken into the oral cavity

Second, positive pressure (+) phase:


Gums compress the oesophagus which agents food, and into the larger mouth cavity (blue arrow) pressure from the palate, squeezing food and nipple (blue arrow) into the pharynx to be swallowed

Positive pressure created as the tongue moves up to the roof of the mouth, creating a seal and forcing the pharyngeal contents into the closed palate ends of the oesophagus and the food passes to the stomach

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Cleft palate prevents effective closure of the pharynx from the nasopharynx and creation of negative intraoral pressure


First phase:



Although the tongue dorsum distended cannot yet negatively pressure a sealed oral cavity, as the palate cannot rise as high as it is allowing air to be drawn in through the nose and/or mouth. The pressure in the oral cavity is still at a level below the ambient air. As little only sealed oral cavity is not exposed from the air, the tongue compression forces the gaps.

A series of negative pressure pulses: When the tongue moves down a further stroke, negative intraoral pressure is built up by creating a narrowing of the oral cavity as air fills in through the nasal cavity. The pressure is the same both sides of the palate.

Second phase:



The tongue moves dorsally (towards palate) for the back of the palate posteriorly (towards pharynx) and the velum contracts upwards. The pharynx contracts, creating negative pressure and effective seal. Real closed oral cavity is created by the pharynx contraction allowing air to draw in through the nasal cavity through oral migration and towards the pharynx.

or Weak positive pressure from the tongue pressing against the roof of the mouth: As the tongue presses the back of the mouth against the roof of the mouth, the pressure in the oral cavity is slightly above the ambient air. The pressure in the nasal cavity, and some downward air pressure,

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CLEFT OF THE HARD AND SOFT PALATE

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Soft Cleft Palate



Submucous Cleft



- Bifid Uvula
- Transparent appearance
- Notch on palpation

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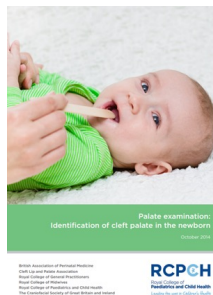
Symptoms

Please visualise the palate and look for potential symptoms

Could it be a cleft?

Can you visualise a uvula?

- Continued difficulty latching at breast
- Clicking sounds during feeding
- Nasal regurgitation of milk
- Tiring during feeding/prolonged feeds
- Rapid sucking with minimal milk transfer
- Weight loss or insufficient weight gain
- Breathing difficulties associated with above symptoms



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Video

learning.rcpch.ac.uk/wp-admin/admin-ajax.php?action=ajax_shortcode&form&content_id=302



Always visualise the palate
Best practice is to use a tongue depressor and torch, as per RCPCH guidelines.



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Feeding

- Difficulties can arise with any cleft type, but are more severe with palatal clefts
- Babies with cleft palate will need assisted feeding using specialist bottles
- Paced bottle feeding approach
- Occasionally, baby will need dysphagia feed assessment prior to introducing oral feeds



MAM Soft Bottle/Orthodontic Teat
Dr Brown's Specialist System

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Breastfeeding Support

Breastfeeding may be possible, depending on the type of cleft, but may not be sustainable

Encourage change of terminology – breastfeeding → breastmilk feeding

Most cleft centres across the UK will loan double breasted pump to assist with feeding

Encourage regular skin-to-skin contact and latching post feeds for comfort

Supplemental Feeding System – consideration based on mothers wishes

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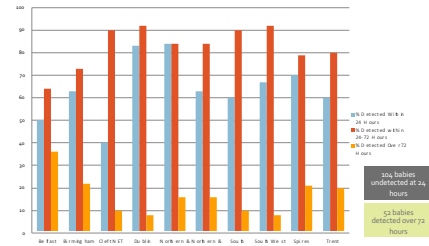
Delayed Detection

- Diagnosis after 24 hours of life considered a delayed diagnosis
- Each year 10-20% of babies, receive a delayed diagnosis of cleft palate

IMPACT..

- Anxiety to parents
- Faltering growth
- Effects feeding choices
- Hospital re-admission

Delayed Detection 2022



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Parents voices

- 'Angry it was not diagnosed properly as baby struggled to feed for 3 days'
- 'I could see that J was not latching on and she was getting increasingly distressed.'
- 'I knew something was wrong, but I was reassured all was normal'

Resources

RCPCH Module:

90-minute free online course



CLAPA

- UK Charity
- Lots of information for practitioners and families
- Referral Information



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NHS CLEFT PALATE IDENTIFICATION
For professionals involved in infant feeding

Could it be a Cleft Palate?
Up to 80% of presentation of clefts involve the palate only, varying in shape and size

Presenting symptoms
Nasal regurgitation during or after feeds
Clicking sounds during feeds
Cardinal difficulty latching at the breast
Tiring during feeds or prolonged feeds
Faltering Growth

Always visualise the palate
Best practice is to use a tongue depressor and touch as per RCPCH guidelines

Incidence and Delayed Detection
Diagnosis after 24 hours of life is classified as delayed

Annually, 10-20% of babies receive a delayed diagnosis of a cleft palate
18% of cleft palates are diagnosed between 1 week and 6 months of age
The impact of a delayed detection for families can be devastating

Cleft Specialist Nurses
Professionals supporting infant feeding are ideally placed to examine an infant's palate as part of their own routine assessments. This additional contact provides opportunities to identify cleft palates that have been missed on the NPT examination and by other health care professionals. We aim to offer greater support through ongoing awareness and training, ultimately reducing delayed diagnosis.

Useful resources
RCPCH Best Practice Guidelines
From 10 minute video bundle

How to Refer
If a cleft is identified, please phone local Cleft Team as soon as possible using information on this QR code



QUESTIONS

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